

Communicating with Patients – Common Sense or a “Black Art”?



I am very fortunate in my role as a strategic medical writer – clients who recognise that I’ve been doing this for longer than it would be polite to admit often ask for my opinion, rather than just give me a set of instructions and tell me to churn out a document. However, what never ceases to amaze me is that whilst discussions of regulatory strategy can certainly become heated, this is nothing compared with the extremes of reaction seen in discussions about patient information.

The most frequently encountered reaction to communicating patient information is apathy, and there are many possible reasons for this. The most usual is that patient information is seen as ‘nothing special’, and something that ‘anyone can write’. Therefore, anyone who has the time or vague inclination is given the task of ‘writing something to go with’ the drug or device. Therefore, when a medical writer is finally approached for help with the situation, explaining to clients why their leaflet has failed its readability test or their ‘Dear Doctor’ letters or sales training are not getting the desired results is met with a mixture of irritation and bemusement.

This is all understandable, of course, and one of the skills required of a medical writer is to manage such reactions and minimise any conflict until a happy client, and hopefully a beautiful and effective document, result. However, it’s worth examining the reasons why a lot of patient information is so poorly communicated, as this has far deeper implications.

Health literacy can be defined as the ability to obtain, process, and understand the basic health information and services needed to make appropriate health decisions and follow instructions for treatment¹. There is certainly no doubt that health literacy and numeracy have huge impacts on patient engagement, compliance and health outcomes. But this is not affected only by an individual’s general ability to read, write, and understand text and numbers, and certainly not just by their overall ‘intelligence’. An individual’s experience of the healthcare system, the complexity of the information being presented, how the material is being presented or explained, and cultural factors (that may influence how decisions are made) all affect the level of ‘health literacy’ or ‘numeracy’ of any individual at any given time.

The quality of patient information is particularly important in the clinical trial setting, when new drugs or procedures are being investigated, and patient understanding of the potential benefits and risks of their involvement is paramount. Poor patient information can lead to both reluctance to join a trial, and poor compliance during it.

Additionally, the increasing influence of patient groups should not be underestimated. The European Patients’ Forum has called for patient group involvement in healthcare policy decisions, and Patient View was formed in 2000 to gather together worldwide health non-governmental organisations (including disability groups, carers’ groups, gender-based

groups), work with, and study, these organisations, and is growing continually in numbers and scale of influence. Patient View conducted a survey that ranked the top 30 pharma companies on six indicators, one of which was ‘the quality of the information for patients which it provides’.

Failure to take medicines properly is a growing problem, and is very common - 50% of people don’t take their medications as prescribed, and this is responsible for 10% of all hospitalisations and over 125,000 deaths annually in the cardiovascular area alone². Shockingly, approximately 10% of adverse drug reactions can be attributed to a communication failure between provider and patient³. Low health literacy is associated with poorer health outcomes and poorer use of healthcare services. It is significantly associated with higher all-cause mortality⁴, and in the US it is estimated to cost \$106-236 billion per year⁵.

So how severe is the problem of poor health literacy? In a recent study of adults presenting to an average city emergency department in the US, 15.5% had limited health literacy, which was associated with increasing age, male sex, non-English first language, non-white ethnicity, limited education, and unstable housing⁶. There is limited information on levels of health literacy in England, however the Skills for Life Survey showed that 1.1 million people in England were functionally illiterate, and approximately 16% of adults have lower literacy skills than those of an average 11-year-old⁷. The figures are even worse for numeracy, with 1.7 million people being functionally innumerate, and it is known that people with a lower numeracy level make larger errors in interpreting medicines’ side-effect risk information. It is therefore very likely that for many people, low health literacy acts as a significant barrier to achieving and maintaining good health.

The need for effective communication is especially important in vulnerable groups such as the elderly or paediatric populations. The elderly population is increasing (there will be around 72 million individuals aged at least 65 in the US in 2030⁸, compared with 38.6 million in 2010⁹ and there are increasing numbers of individuals with dementia. Poor reading skills are particularly problematic in the elderly because of their high prevalence of chronic disease and their need to understand healthcare information – often their diseases have complex treatment regimens, and require multiple consultations with different clinicians. Adherence to medicines by children and young people is even worse than that of adults, despite the oversight of parents¹⁰.

Tackling the problem of poor patient information has its own challenges. We live in an increasingly information-rich environment, and patients are one of the most information-hungry sub-sections. An MHRA survey in 2005 showed that people want more medicines information, and that they value the patient information leaflet more than any other source except doctors and pharmacists. Unfortunately, they do not always understand the patient information they receive. Studies have consistently shown that patient

education leaflets are written at an excessively high reading level. One survey showed that almost a third of patients did not understand their medicine label instructions¹¹ and in a UK outpatients study of COPD patients, 15% were not able to use the written information they had been given¹².

As society becomes increasingly technologically aware, patients are turning to the internet for health information. 80% of internet users look for health information online¹³ and a survey of 178 cancer listserv users showed that 35% chose the internet as their preferred source of health information. Given that well-known studies show that patients recall less than 50% of what they are told during their consultations^{14,15} it is perhaps understandable that patients would turn to the internet for further information or explanation. Unfortunately, not only are there myriad uncontrolled and un-reviewed sites available, but the internet does not necessarily offer more easily understandable healthcare information – even on reputable sites. As examples, information on breast cancer prevention obtained from the National Cancer Institute's website has been assessed as being written at far too high a level¹⁶, and there is marked variation in the quality of available patient information on websites about the treatment options for Crohn's disease and ulcerative colitis; few of which provide high quality information¹⁷.

There is no doubt that patient information is important, and high quality information can make a hugely positive impact. It has been shown that patients who received specific preoperative information on the procedure and written instructions on postoperative care experienced less pain, consumed fewer analgesics, and had an earlier return to daily activities¹⁸.

So what can be done to improve the degree of health literacy in patient information? The documents need to be written for the right audience. This means taking into account what the reader wants to know, what they need to know, and what they might know already. Patients prioritise four key points of information when they are reading about medicines: the side-effects they might get from the medicine, what to do and what not to do, what the medicine does, and how they should take it.

The medical writer's job therefore is to provide this information in a format the patient can understand and access as easily as possible. Whilst this might sound very straightforward, it is often far from simple, particularly considering that English might not be the first language of the reader, or that they might be affected by mental or visual impairment, or might not be able to read at all (necessitating the careful use of visuals). It takes experience and skill to identify potential hurdles to understanding, let alone to counter them, but there are some general guidelines that can help along the way.

To be effective, patient information should focus on eliciting key behaviours from the patient e.g. taking a tablet at the right time, with food — not lengthy and unnecessary detail about biochemistry and pathology. Yet many patient leaflets begin with a lengthy discussion of the disease area or physiology, instead of explaining to the patient what they need to do and why they need to do it.

There are a number of tools and techniques which can

be employed to make documents more 'patient-friendly' such as style and formatting changes, sentence structure, and grammar and vocabulary considerations. Information should be given with short words and short sentences, and only essential information should be included, rather than information overload. Long or unfamiliar words are often difficult to understand, and they slow down reading speed. Content should be limited to one or two key objectives, and should be appropriate for the age and culture of the target audience.

The average reading ability of the general public means that text should be written at or below the level of a 12-year-old, and short paragraphs and the active voice should be used. Humans have a cognitive preference for picture-based information, and research has shown that using pictures, including cartoons or pictographs with verbal explanations and use of models, can greatly increase patient understanding and retention of information. In one study, mean correct recall of information was 85% with pictographs and 14% without¹⁹. Another study found that patients receiving wound care instructions with cartoons were able to answer questions correctly 46% of the time three days later, compared to only 6% of patients who received only written instructions²⁰. However, this should be used with care, as leaflets that become too 'cartoon-like' can be perceived as patronising by adults, and all images should be age- and culture-sensitive.

Readers will very rarely put effort into trying to decipher what a sentence or paragraph means – they just skim-read it and move on. If the message can't be gleaned from a quick skim of the text, they will miss the point and the information leaflet is wasted.

Using tools like these can lead to more effective communication with patients and thus higher rates of recruitment, retention and compliance in clinical trials, and lower incidence of side-effects, and more effective use of medicines. However, there is also a certain amount of knowledge and expertise needed to refine the documents even further, and so to maximise the effectiveness of the document for its intended audience. Once they have written the text, good medical writers will check it for 'readability'. Although one well-known tool for this is the Flesch-Kincaid readability score, which is a useful guide for measuring how complex a piece of text is, it also has its drawbacks. The score is based primarily on word and sentence length without considering content or vocabulary. For example, the sentences 'Cat hat is big sat on a mat. Fox stared mouse nose big hat.' have a Flesch readability ease score of 100 (the highest possible), showing that they are very easy to read. However, they are total nonsense and impossible to understand.

Therefore, it is extremely useful to have patient materials reviewed by people as close to the target audience as possible — ideally patients with limited literacy skills — to ensure that the information in the format it has been written in can be understood and interpreted correctly. The Commission on Human Medicines Expert Advisory Group on Patient Information was convened from 2006–09 to work on improvements to medicines information for patients at both a national and European level, and in 2005, the European

Commission introduced a requirement for pharmaceutical companies to undertake ‘consultations with target patient groups’ to ensure that patient information leaflets were usable and understandable for patients²¹. The Commission’s guidance included a recommendation for user testing of patient information leaflets, and this testing is now normal in the EU. User testing involves one-to-one interviews with potential users of a medicine, to determine whether they can find and understand key pieces of information in the patient information leaflet²².

The particular needs of specific groups are also being addressed. Children and young people often feel excluded from discussions about medicines, especially regarding side-effects, but in the UK, a patient information leaflet has been produced for children and young people by a pharmaceutical company in consultation with the University of Leeds and Luto Research Ltd. This leaflet contains an extra section entitled ‘Information for children and young people’, and all the sections are written as though the child or young person taking the medicine is reading them.

Low health literacy is a recognised issue in healthcare communications. However, instead of trying to identify vulnerable groups with particularly low health literacy or numeracy, which can be a difficult and often demeaning process for the participants, wouldn’t it be more sensible to make the information understandable and accessible by all? This is not ‘dumbing down’ patient (or doctor, or medical sales training) information. Instead, it is creating written information in a form that all readers prefer.

An extraordinary amount of time, effort, and money is put into creating and marketing medicines – doesn’t it make sense to have the patient information written by specialists who can maximise the chance of the medicine being used in the way it was meant to – or even used at all? I have lost track of the number of clients who have looked bemused when I asked about the experience level of the person writing their patient information, and have been told that ‘whoever had time’ had produced the information. Most people believe that writing for patients is ‘common sense’ and that, just like driving well, anyone can write well for patients. Far be it from me to criticise anyone else’s driving, but the road traffic statistics indicate that not everyone is able to drive as well as they might believe ... is it really unreasonable to suggest that not everyone can write as well for patients as they might wish?

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